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PRE-DIALYSIS
CHRONIC KIDNEY DISEASE

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There are 5 stages of chronic kidney disease (CKD) that determine how well your kidneys are functioning.

A test called eGFR (estimated Glomerular Filtration Rate) is a blood test used to measure your kidney function. It is sometimes referred to as a percentage of normal kidney function.

If your kidneys filter less well, your eGFR falls.
Once your level has fallen to below 30% (Stage 4) you have entered the pre-dialysis stage.

(See “About Your Kidneys”)

WHAT DOES PRE-DIALYSIS STAGE MEAN?

This means that your kidneys may not be filtering the blood and removing excess fluid as effectively as before.

When eGFR falls to 15% (Stage 5) it may need to be managed with dialysis, a transplant or conservative care.
At this stage, you will attend a specialist kidney clinic.

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WHEN YOUR KIDNEY FUNCTION FALLS TO STAGE 4-5, HOW WILL YOU FEEL?

You may start to experience common symptoms caused by the build up of waste products in your blood as the kidneys are not able to filter or ‘clean’ these from your body efficiently.

Whilst some people may not feel ill, some will experience symptoms that are referred to as ‘uraemia’ which are explained below.

Some symptoms can also be due to anaemia as your kidneys are no longer producing a sufficient amount of a hormone called Erythropoietin that helps red blood cells survive and grow.

WHAT ARE THE SYMPTOMS OF URAEMIA?

Symptoms of uraemia may include:

- High blood pressure
- Tiredness
- Trouble concentrating
- Loss of appetite and weight loss
- Nausea and vomiting
- Itching

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- Decreased sexual interest / performance
- Trouble sleeping
- Shortness of breath
- Swollen ankles, puffiness around the eyes.

WHAT BLOOD TESTS MAY BE DONE WHEN YOU COME TO CLINIC?

To see how well your kidneys may be functioning, the 3 common blood tests are:

CREATININE: This is the breakdown product of muscle which the kidneys excrete. The result can be affected by age and gender and helps doctors to determine how well the kidneys are functioning.

Less than 100micro-mols/l Normal

101-499 micromols/l Requires monitoring

Greater than 500 micromols/l. High

PRE-DIALYSIS

POTASSIUM: This is a natural chemical or electrolyte which occurs in many foods. The kidneys regulate the levels of potassium in your body as very high levels can cause irregular heart rhythms. As your kidney function declines you may need to restrict foods that are high in potassium.

3.5 – 5.0 mmols Normal → **5.1 – 6.0 mmols OK** → **6.1 – 6.9 mmols High** → **Greater than 7.0 mmols Very high**

PHOSPHATE: This is a mineral in food that can build up in your body as a result of a reduced kidney function. High levels of phosphate can cause itching and sore red eyes. In the long term, high phosphate levels can cause brittle and weak bones, muscle and joint pain, and may lead to serious heart problems, so advice on diet and medications may be given to help. (See “Common Medicines used in CKD”)

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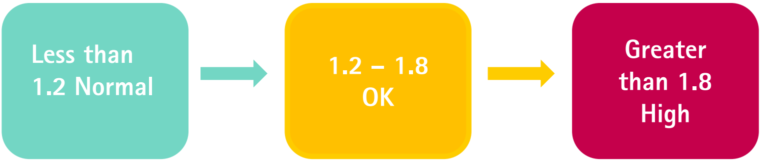

WHAT CAN YOU DO FOR YOURSELF AT THIS STAGE?

Whilst some kidney function can remain stable for years, other people may find that their kidney function continues to decline.

If your kidney function is at stage 4 or 5 there are some lifestyle changes that you could make to prevent other problems with your health occurring. These include:

WEIGHT REDUCTION

Losing weight can help reduce blood pressure and the risk of developing heart problems and diabetes.

DIABETES

If you have diabetes, you should aim to get good blood sugar control with diet and/or medication.

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SMOKING

Do you need help to stop smoking?

This would help to reduce potential problems with your heart and circulation.

BLOOD PRESSURE

Your health care team will aim to reduce your blood pressure if necessary. Exercise can help to reduce weight and improve blood pressure.

WHAT WILL YOUR HEALTHCARE TEAM RECOMMEND?

VACCINATIONS

Your nurses and doctors may recommend at this stage to have an annual flu vaccination and the pneumococcal vaccination every 5 years.

As a precaution, you will be tested for Hepatitis B and C before starting dialysis treatment (and at regular intervals during dialysis) because of the risk of spreading blood borne viruses. Your doctors may wish you to have the Hepatitis B vaccination at this stage.

PRE-DIALYSIS

If it is likely that you may have a transplant in the future you may also be screened for Human Immunodeficiency Virus (HIV).

DIET

As your kidney disease progresses, certain substances in your food that the kidneys would normally remove may build up. These include potassium and phosphate.

In addition, a diet that is high in salt (sodium) can not only make you thirsty but also lead to a buildup of fluid in the body and potentially a problem with high blood pressure.

A dietician may therefore ask to speak to you to give advice on how to prevent these problems from occurring.

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FLUID BALANCE

The kidneys are responsible for removing excess fluid from the body. If the kidneys are not working properly, there may come a time when they can no longer do this efficiently. This means that you might have to monitor your fluid balance to ensure that the amount of fluid that goes into your body equals what comes out (i.e. in terms of urine and sweat). This can be achieved by restricting how much you drink and, if prescribed, by taking medicines called diuretics that help the kidney produce more urine.

You might be asked to weigh yourself regularly as a sudden weight gain may indicate that the amount of fluid in the body is increasing.

Other signs and symptoms of excess fluid include:

- Swollen ankles
- High blood pressure
- Puffy eyes
- Shortness of breath – especially when trying to lie down.

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It is important to remember that if you suddenly become very short of breath, you should immediately seek expert help from your doctors and nurses, as excess fluid may have built up in your lungs.

WILL YOU NEED TO TAKE MEDICINES?

Medicines can be used to help with a variety of symptoms caused by your kidney disease. Although the amount of medicine that you need to take may steadily increase, it is important for your health that you take all of these medicines as prescribed.

IMPORTANT:

- Some medicines can reduce kidney function, so you should always remind your doctors and pharmacists that you have kidney disease.
- Do not buy any medicines over a shop counter without seeking advice. In particular, you should avoid some pain killers known as non-steroidal anti-inflammatory drugs.
- If you are prescribed new drugs by your doctor, do not be afraid to ask what they are for.

(See “Common Medicines used in CKD”)

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WHAT ELSE DO YOU NEED TO THINK ABOUT?

If your kidney disease progresses you may reach a point at which you will need to consider other treatments if your kidneys fail. Discussions for this may start early as it is recognised that people cope better with the future if they have time to adapt and plan their care.

Treatment options (although not all are available in some countries) include:

Hemodialysis
This involves coming into the unit 3 times a week

Home Hemodialysis
Together with a carer you can be trained how to do this at home, if the environment is suitable.

Peritoneal Dialysis
A treatment you can manage yourself at home after training

Transplantation
This is not applicable to all people as it can depend on individual health and age

No Dialysis
Ths is occasionally considered for the very frail person for whom dialysis would not improve their life expectancy

PRE-DIALYSIS

Whichever dialysis option you chose, you will need to have dialysis access inserted to allow you to be attached to a dialysis machine.

There are two types of dialysis access for HAEMODIALYSIS:

- A Fistula. This is a small operation that is needed to join a vein and an artery together. This is usually in the arm and done under a local anaesthetic. It allows the vein to become bigger so that 2 dialysis needles can be inserted for each dialysis session and then removed at the end of treatment. The operation needs to be done 4-6 weeks prior to treatment commencing.
- A tunnelled catheter. This is inserted into a large vein in the neck (or occasionally in the groin) under a local anaesthetic. This can be used immediately.
  (See “Haemodialysis”)

PRE-DIALYSIS

For PERITONEAL DIALYSIS, a soft silicone tube called a Tenchkoff Catheter is inserted into a cavity in the abdomen at least 2 weeks before you need to start treatment.
One end of the catheter will be in the abdomen while the other will come out of your skin and is known as the exit site. The Tenchkoff catheter remains in the abdomen but can be hidden under your clothes.
(See “Peritoneal Dialysis”)

TRANSPLANTATION is when a kidney is removed from a human donor and then placed inside of your body. If the transplant is successful, it will take over the function of your kidneys.

There are 2 sources of transplanted kidneys:

- Living donors; those who have close tissue matches and who agree to give you a kidney
- Cadaveric donors; people who have agreed to donate their kidneys after they have died.

PRE-DIALYSIS

Not everyone is suitable to be considered for a transplant as you have to be able to cope with the operation physically and emotionally. The doctors may order a series of tests to see if a transplant is possible. Some people with diabetes may be considered for a combined kidney/pancreas transplant.

It is important to remember that not all kidney transplants will work. Whilst this can sometimes be only a temporary problem, for others it can be permanent.
(See “Kidney Transplant”)

NO DIALYSIS OPTION: This is sometimes chosen by those who have serious health problems as well as kidney failure. Dialysis may therefore not improve or lengthen their lives. Having been given a clear view of the advantages and disadvantages of dialysis treatment, these people will decide with the help of their loved ones not to pursue dialysis treatment.
Not having dialysis will lead to death at some point but you will be offered care and support by the renal team with medication that can keep you active and independent for as long as possible.

PRE-DIALYSIS

PSYCHOLOGICAL ASPECTS OF CARE

Finding yourself diagnosed with chronic kidney disease turns your world upside down. It is an experience that can leave you feeling overwhelmed. It provokes a wide range of emotions as you begin a process of accommodating to this new and dramatic change in life. With diagnosis this change can affect family life and relationships, social life and employment, no matter what your age. People can experience some common reactions.

WHAT ARE SOME OF THE COMMON REACTIONS?

People react differently and use different words to describe what they feel when they are told their kidneys have failed. Whatever words are used to describe it, they convey an emotional reaction to this diagnosis. Coping mechanisms are employed to help cope with the emotional stress engendered by diagnosis.

PRE-DIALYSIS

SHOCK - I CAN'T BELIEVE THIS IS HAPPENING TO ME

The most common word used is 'shock', summed up in the phrase 'I can't believe this is happening to me'. People can feel in a daze, unable to speak or articulate how or what they feel.

This phase should pass in a relatively short time.

DENIAL – I DON'T WANT TO THINK ABOUT IT

Another common reaction is to retreat into denial. Denial is often expressed by the phrase 'I don't want to think about it'. Denial has some advantages, and is a valid short-term strategy.

Its danger lies in it becoming a long-term strategy as treatment regimens demand the engagement of the person diagnosed.

PRE-DIALYSIS

ANGER – WHY ME?

Anger is a normal emotion and can be aroused when you feel trapped or under undue stress.
It is summed up in the phrase 'Why me'? Anger can also be positive or negative.
As a positive emotion it can help harness your energy which will allow you to respond in a healthy way to diagnosis and treatment. In its negative form it can become destructive and rather than engage people to support you, it can result in isolating those you most need.

FEAR – WHAT IS GOING TO HAPPEN TO ME NOW?

Fear is the normal reaction to something that is unexpected or unknown. Fear finds expressions in phrases like:

- 'What is going to happen to me now?'
- 'Am I going to die'?

Fear has the potential to paralyse, making it difficult for you to think straight or to work out to whom you should turn for support. While some level of fear will probably always be present, this phase should pass rather quickly.

PRE-DIALYSIS

DEPRESSION

The knowledge that you have a chronic condition requiring life-long treatment can be overwhelming. For some people the only way they know how to cope is to withdraw into a world where they feel safe and secure. It leads to the person becoming distant and isolated and can leave the family feeling impotent and not knowing what to do.

If depression is an issue, support (medical and psychological) should be sought.

RELIEF

Some people experience a sense of relief when they are diagnosed. One set of worries can be set aside as they know that treatment is available for the condition they have.

HOW LONG WILL THESE REACTIONS LAST?

As individuals we all react differently to situations we encounter. Some people adopt the attitude ‘just get on with it’ and can harness their emotional energy and accommodate quite quickly.

Others can feel stuck and will require emotional support.

PRE-DIALYSIS

WHAT CAN YOU DO TO HELP YOURSELF?

There are a number of strategies you can use to help you accommodate to your diagnosis and subsequent treatment. To help you accommodate, consider the following questions:

- Identify what this diagnosis means for you and your family.
- Acknowledge your thoughts and feelings and begin to work through them.
- There may be a number of treatment options open to you. Find out about each one, discuss it with your family and come to a decision.

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WHAT ELSE CAN YOU DO TO HELP YOURSELF?

SET REALISTIC GOALS

It is important not to let dialysis control your life. If you set yourself some realistic goals it will give you a sense of control and purpose which will enable you to place your diagnosis and treatment within the context of your whole life. At times, when it appears the going is more difficult, recalling these goals can help you get through the difficulties.

It is important to recognise what you can and cannot change. You cannot change the fact that your kidneys have failed but there is room for manoeuvre when it comes to how you manage your treatment.

PRE-DIALYSIS

DEVELOP A HEALTHY LIFESTYLE

The renal diet will become a key part of your treatment. This can be problematic for some people as they find the diet restrictive especially if they cannot eat some of their favourite foods.

Keeping to the diet is for your overall wellbeing. With the help of a dietician look for kidney friendly recipes to broaden the range of food you can have.

Exercise is also important. Sometimes, due to fatigue, exercise may be the last thing you want to think about or do. It is important to exercise as regularly as possible, all the time acknowledging the limitations imposed by your illness. (See “Physical Exercise”)

CONTINUE TO BE INVOLVED IN SOCIAL ACTIVITIES

There is always the temptation, due to fatigue and the demands of treatment, to withdraw from social activities and to set aside interests and hobbies you have.
Being involved in family occasions, socialising with friends, or retaining interest in hobbies can all remind you that you are a whole person, not just someone with chronic kidney disease.

FIND A SUPPORT NETWORK

The staff on your renal department may be able to help you to find out what support networks are available to you and your family.

WATCH HOW YOU THINK?

There are going to be times when the going gets tough and you can easily fall into a negative form of thinking. Life can be seen exclusively from a negative viewpoint and the more positive aspects are lost. Becoming aware of this negative thinking allows you the opportunity to balance the negative with some positive thinking.

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SEEK PROFESSIONAL HELP

Some people find it very difficult to accommodate to their illness. If this happens to you, seek the support of a counsellor, psychologist or social worker who will be able to help you work through the difficulties you are experiencing.

WHERE CAN YOU FIND MORE INFORMATION?

You can ask for more information from members of your local healthcare team at your local hospital or clinic. Information can also be obtained through organizations dedicated to supporting kidney patients and their families.

Information on the Internet:
Be careful with the information published on the internet, not all websites provide good quality health information:

- Check the information found on the Internet with your nurse (be cautious not to follow all you read unless you have checked the information with your healthcare professional).

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KEY POINTS TO REMEMBER

- If your level of eGFR has fallen to below 30% (Stage 4) you have entered the pre-dialysis stage of kidney disease.
- When your kidney function falls to stage 4-5 you may start to experience symptoms of uraemia
- If your kidneys do fail there are various treatment options that might be offered to you
- You are not alone, help and support is available to you.
- Keep the lines of communication open with your healthcare team, your family and friends. If they know what is happening then they can help and support you.
- If your reactions concern you, seek help (professional or otherwise) and support.
- Keep your thoughts positive: ‘Yes I can do this’.
- If you don’t know or are unsure – don’t be afraid to ask.

The Patient Education Document is sponsored by B. Braun Avitum AG.

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